

# Feeling lost, not knowing where you are...?

## What is disorientation?

Disorientation is a state in which a person may not know where they are, who they are, or what day it is. People may look dazed or have a lack of clarity in their thoughts. It can be hard for them to make sense of what is happening around them. Some people may appear confused and unclear about things.

## How can I detect confusion or disorientation?

- Not knowing what day, date or time it is.
- Uncertain about where you are.
- Not sure of who you are.
- A lack of attention.
- Disorganised thinking.
- Lower level of consciousness, for example seeming very drowsy.
- A lack of clear thinking or behaviour.
- Feeling bewildered, overwhelmed or puzzled.
- Getting lost easily.
- Losing your train of thought.
- Feeling uncertain of how to do things or get places.

## 'Alan's' Story

'Alan' is a man in his early sixties diagnosed with a Glioblastoma (high grade tumour) in his left parietal lobe. He is very unwell and has undergone several courses of cancer treatment. 'Alan' has been showing some confusion in that he will stop in the middle of a speech, appearing to lose his train of thought. He has difficulty keeping track of the days and sometimes gets confused about what month it is. 'Alan' often appears aimless at home as he gets up out of his chair and wanders

into the kitchen without any plan of what he is doing. He needs help all the time when he goes out, as he is likely to get lost and no longer feels safe outside his home. His wife has now left work to be his full time carer and has to give him daily support and comfort.

## Strategies

### For the person with a brain tumour

- Use a whiteboard or timetable to write out your daily and weekly routine (Resource sheet – Timetable).
- Use lists to outline tasks that you need to do and tick off each task when it is done.
- Cross off days on a calendar to identify the day and date.
- Ask someone to come with you when you go to appointments.

### For the carer or family member

- Maintain a regular routine.
- Label rooms or objects with names or symbols.
- Use a wall calendar and cross off the days with your family member.
- Let the person know daily, what day it is and the date.
- Give reassurance and reminders of where they are and where they are going.
- Give them help in making decisions.
- Try to give them only one piece of information at a time.
- Limit the number of people in the room at any one time.
- Keep noise levels as low as possible.
- Lay clothes out for the day if they are having difficulty working out what to wear.

## KEY FACTS

A survey of people with a brain tumour found that:

- 37% frequently became confused.
- 13% were frequently or almost always disorganised.

- Try to only give simple, single step instructions and repeat them if needed.
- Make sure they feel safe and keep an eye on them to give any help they need.

## Questions to ask your health professional

- What is the cause of the confusion?
- Is it related to the tumour itself?
- Is it related to the treatments given for the tumour or other medications?
- Could the confusion/ disorientation be an unrelated medical condition and does this need treatment in itself?
- Do I/we expect the confusion/ disorientation to get better or worse over time?
- Are there any medications that can help the problem?
- Are there any diet or lifestyle factors that can help the confusion/ disorientation?
- Will a psychologist be able to help treat this problem?



**Links to other information:**

- [http://www.health.qld.gov.au/abios/documents/behaviour\\_mgt/changes\\_strategies.pdf](http://www.health.qld.gov.au/abios/documents/behaviour_mgt/changes_strategies.pdf)